

AMENDED IN ASSEMBLY MAY 8, 2000

AMENDED IN SENATE APRIL 13, 2000

Senate Concurrent Resolution

No. 75

Introduced by Senators Lewis, Alarcon, Alpert, Bowen, Burton, Costa, Escutia, Figueroa, Hayden, Hughes, Johannessen, Johnson, Karnette, Kelley, Knight, Monteith, Morrow, Mountjoy, Murray, Perata, Rainey, Speier, and Vasconcellos

(Coauthors: Assembly Members Aanestad, Ackerman, Alquist, Aroner, Baldwin, Bates, Battin, Baugh, Bock, Brewer, Calderon, Campbell, Cardenas, Cardoza, Cedillo, Corbett, Correa, Cox, Cunneen, Davis, Dickerson, Dutra, Florez, Gallegos, Granlund, Havice, Hertzberg, Honda, House, Jackson, Keeley, Knox, Kuehl, Leach, Lempert, Leonard, Longville, Lowenthal, Machado, Maddox, Maldonado, Margett, Mazzoni, McClintock, Nakano, Olberg, Oller, Robert Pacheco, Rod Pacheco, Pescetti, Reyes, Romero, Runner, Scott, Shelley, Steinberg, Strickland, Strom-Martin, Thompson, Thomson, Torlakson, Vincent, Washington, Wayne, Wesson, Wildman, Wright, and Zettel)

March 29, 2000

Senate Concurrent Resolution No. 75—Relative to
Friedreich's Ataxia Awareness Day.

LEGISLATIVE COUNSEL'S DIGEST

SCR 75, as amended, Lewis. Friedreich's Ataxia
Awareness Day.

This measure would proclaim May 20, 2000, as Friedreich's Ataxia Awareness Day.

Fiscal committee: no.

1 WHEREAS, Friedreich's ataxia is an inherited,
2 progressive neurological disorder, usually diagnosed in
3 childhood, that causes muscle weakness and loss of
4 coordination in the arms and legs; impairment of vision,
5 hearing, and speech; scoliosis; diabetes; and a serious
6 heart condition. Most patients need a wheelchair
7 full-time by their twenties and, in later stages of the
8 disease, many become completely incapacitated. Life
9 expectancy is reduced to early adulthood. There is
10 currently no effective treatment or cure for Friedreich's
11 ataxia; and

12 WHEREAS, Although there is no treatment or cure
13 available to Friedreich's ataxia patients and families, they
14 have more and more reason for real hope. An
15 extraordinary explosion of research findings has followed
16 the identification of the Friedreich's ataxia gene in 1996.
17 Since that discovery, research scientists have learned a
18 great deal about the disorder. They have identified and
19 analyzed the protein that is deficient in these patients,
20 and determined that the deficiency results in faulty iron
21 metabolism, reduced mitochondrial function, and
22 cell-killing oxidative stress. Scientists have also developed
23 model Friedreich's ataxia systems in lower organisms and
24 are testing these systems in human cell cultures and
25 patients. Therapeutic clinical trials of promising drug
26 compounds are now underway, with encouraging
27 preliminary results; and

28 WHEREAS, Investigators are increasingly optimistic
29 that they are drawing closer to understanding more fully
30 the causes of Friedreich's ataxia and to developing
31 effective treatments. Of course, the impact of a
32 breakthrough in this disorder will not be limited to
33 Friedreich's ataxia. As the Director of the National
34 Institutes of Health (NIH) recently reported to the
35 Congress, "As with progress in many rare diseases, what
36 we discover about cellular changes and therapeutic



1 approaches in Friedreich's ataxia may lead us to
2 important insights about more common disorders"; and

3 WHEREAS, Within the NIH, the National Institute of
4 Neurological Disorders and Stroke (NINDS) has primary
5 responsibility for sponsoring research on Friedreich's
6 ataxia and the other neurological disorders. The NINDS
7 conducts research on Friedreich's ataxia and other forms
8 of inherited ataxias at its facilities at the NIH and supports
9 additional studies at medical centers throughout the
10 United States and elsewhere; and

11 WHEREAS, Augmenting these
12 government-sponsored efforts are programs supported
13 by patient advocacy foundations and industry. The
14 intensifying cooperation among these various sources of
15 support for this research and the multidisciplinary efforts
16 of thousands of scientists and health care professionals,
17 provides powerful evidence of the growing hope and
18 determination to conquer Friedreich's ataxia; now,
19 therefore, be it

20 *Resolved by the Senate of the State of California, the*
21 *Assembly thereof concurring,* That the Legislature
22 hereby proclaims May 20, 2000, as Friedreich's Ataxia
23 Awareness Day; and be it further

24 *Resolved,* That the Secretary of the Senate transmit
25 copies of this resolution to the author for appropriate
26 distribution.

